Title

Educational Intervention Improves Knowledge in Deep Brain Stimulation Candidates & their Caregivers

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Educational Intervention Improves Knowledge in Deep Brain Stimulation Candidates & their Caregivers

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of Nursing Practice

by

Nasrin Esnaashari

2020

ABSTRACT OF THE DISSERTATION

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Deep Brain Stimulation Candidates & their Caregivers

by

Nasrin Esnaashari

Doctor of Nursing Practice

University of California, Los Angeles

Professor Paul M. Macey, Co-Chair

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Background. Neurological disorders, such as Parkinson's disease (PD) and Essential Tremors (ET) are among the leading sources of disability. Several studies have demonstrated the efficacy of Deep Brain Stimulation (DBS) therapy for motor symptom control in a selected group of patients with PD or ET. However, patient education materials are not consistently available for DBS candidates or caregivers. The purpose of this quality improvement project was to examine the effects of an Advanced Practice Registered Nurse-led comprehensive DBS Education-Based Intervention program (DBS-EBI) on DBS knowledge and satisfaction in patients with PD or ET and their caregivers immediately after, and two weeks after DBS-EBI.

Methods. A single group design with three time-points was used to examine knowledge and satisfaction after DBS-EBI in patients with PD and/or ET and caregivers. Knowledge was

measured using the Knowledge Evaluation Form before (T1), immediately after (T2), and two weeks after (T3) The Program Evaluation Form was used to measure satisfaction (T3).

Results. Patients (n=7 PD; 2 ET; 1 PD + ET, 58.8 ± 17.28 years) had a significant change in knowledge (χ^2 df=2, 13.2, p = 0.001), with scores at T2 > T1 (p = 0.007) and T3 > T2 (p = .01). Caregivers (n = 12; 58.0 ± 15.33 years) also had significant change over the three time-points (χ^2 df=2, = 10.82, p = .004) with scores at T3 > T2 > T1 (p = 0.05). Patients found the DBS-EBI was helpful (33%), educational (33%), and had good information (33%). Caregivers thought that the most important information were related to before and after surgery (66.7%) and precautions to minimize risk for infection (50%). Both patient and caregivers (60%) had positive comments on the DBS-EBI PowerPoint presentation and the Pamphlet that was given for reference at home.

Conclusion. The DBS-EBI showed a significant increase in knowledge and the majority of participants were satisfied with the DBS-EBI. A nurse-lead DBS-EBI program can improve DBS knowledge, and may be a useful practice across many DBS centers, given that DBS knowledge is associated with improved health outcomes and quality of care for DBS patients and caregivers.

The dissertation of Nasrin Esnaashari is approved.

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2020

This dissertation is dedicated to my family including my supportive husband Gary, my daughters Tannaz, Naz, Targol, and my beautiful grandchildren Aidan and Laila. Their everlasting love made this journey possible.

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Acknowledgements

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PUBLICATIONS AND PRESENTATIONS

Amar, A. P., Larsen, D. W., **Esnaashari, N**., Albuquerque, F. C., Lavine, S. D., & Teitelbaum, G. P. (2001). Percutaneous transpedicular polymethylmethacrylate vertebroplasty for the treatment of spinal compression fractures. *Neurosurgery, 49*(5), 1105-1114; discussion 1114-1105.

Esnaashari, N., Jacobs, E., Hodge, F., Macey, P. & Brecht, M. (2020). Education for deep brain stimulator candidates and caregivers. Research day, University of California School of Nursing, California, May 7, 2020.

Esnaashari, N. (2020). Patient expectations before and after DBS, a Mindful discussion. 25TH Van Der Meulen Neurology Conference, University of Southern California, California, March 7, 2020.

Esnaashari, N. (2020). Deep brain stimulation programming, 25th USC Parkinson's Disease Patient Symposium, In Partnership with Parkinson's Foundation, University of Southern California, California, May 23, 2020.

Esnaashari, N., Chen, S., Hui, J., & Togasaki, D. (2016). Patient expectations and outcome after DBS: 24 months of data. 4th World Parkinson Congress, World Parkinson Coalition, Portland, Oregon. September 2016.

Esnaashari, N., Liang, J., Lio, C., Hui, J., & Togasaki, D. (2015). Patient expectations and outcome after DBS: 12-month results, 19 TH International Parkinson's Disease and Movement Disorder Society (MDS), San Diego, California, June 2015.

Esnaashari, N., Hui, J., Hwu, J., Lio, C. & Togasaki, D. (2012). Patient expectations and outcome after DBS: 6 months data, American Neurological Association, Boston, Massachusetts, October 2012.

INTRODUCTION

Introduction

The proportion of aging Americans have increased from 3.1 million in 1900 to 35.0 million in 2000 (Census.gov. 2016). Neurological disorders, such as Parkinson's disease (PD) and Essential Tremors (ET), are among the leading sources of disability in this group (Dorsey et al., 2018). Among progressive neurological illnesses, PD and ET are the most common after Alzheimer's disease (Schneider, Novak, & Jech, 2015). While the financial burden of PD or ET from a societal perspective is not fully understood, PD and ET treatment options are complicated and costly (Carter et al., 2017). Since the 1990s, deep brain stimulation therapy (DBS) has been shown to be one of the most effective and promising treatment options for motor symptoms in suitable candidates with PD and ET (Doğru Hüzmeli & Yılmaz, 2018). DBS is a permanent device that is surgically implanted. After DBS placement, patients and caregivers must manage DBS-therapy at home through the remainder of recipients' lives. In most clinical settings, little if any, education is offered before the implantation of the device. Therefore, the purpose and objectives of this quality improvement (QI) project were to evaluate the effect of a DBS Education-Based Intervention (DBS-EBI) on DBS knowledge acquisition among adult patients with PD or ET and their caregivers, as well as to assess patient and caregiver satisfaction with the DBS-EBI. Specific aims were to 1) compare changes in DBS knowledge scores before and after delivery of a DBS-EBI and 2) describe satisfaction levels among patients and caregivers after delivery of a DBS-EBI.

A deep brain stimulator (DBS) is a surgically implanted permanent device for the treatment of Parkinson's disease (PD) and Essential tremors (ET) that requires life-long management by the patients and caregivers in the home setting. Many studies have shown the

efficacy of DBS therapy (Smith, Pahwa, Lyons, & Nazzaro, 2016), but very few have focused on patient or caregiver education (Dinkelbach, Moller, Witt, Schnitzler, & Sudmeyer, 2017). Currently, there are no DBS-specific education guidelines, teaching principles, or standardized approaches to DBS education for patients or caregivers.

Therefore, this QI project aimed to determine the effect of a novel DBS Education-based Intervention (DBS-EBI) on knowledge and satisfaction among patients and caregivers.

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THEORETICAL FRAMEWORK

Social Cognitive Learning Theory (SCLT) is the conceptual framework used to guide the content development for the DBS-EBI. The SCLT feedback system provides an opportunity for learners to describe what they have learned and retained based on their personal skills and learning style (Taylor & Hamdy, 2013). This framework endorses the importance of learners' cognition, perception, and memory. Social Cognitive Learning Theory allows the learners to align the learning process with their personal needs and to structure information according to their cognitive capacity (Taylor & Hamdy, 2013).

LITERATURE REVIEW

Literature Review

The methodology for article selection was the subject matter of DBS and the synergy among the six chosen articles to support the DNP scholarly project. In contrast to medical management that has been around for many years, DBS is a relatively new treatment option for motor symptom control in PD and ET, (Kalia & Lang, 2015). The benchmark for article selection was based on date published, support for the PICOT question, and sample

characteristics in PD and ET patients, sample size, and research design. Selected articles provided evidence for DBS therapy as a valid treatment option for suitable candidates, but no studies focused on DBS-education. Moreover, the deficiency of standard DBS education was significant. The shortage of DBS education literature signifies the purpose of this pilot project that aims to improve DBS-knowledge among recipients and caregivers.

Synthesis

Dinkelbach, Moller, Witt, Schnitzler, and Sudmeyer (2017) examined the role of DBS education and other PD characteristics that enhance candidates' agreement for a referral to a DBS specialized center for a DBS surgery evaluation. Retrospective data analysis of 264 patient files revealed that DBS education was positively correlated with the decision to accept the DBS treatment option and was reportedly a useful tool for considering DBS acceptance among suitable candidates. The study participants received an educational packet, which included a 26-page detailed information booklet with a 4-minute digital video-disc (DVD) film of DBS procedure. The majority (78.4%) of DBS candidates stated that the DBS educational material was beneficial and showed a highly significant correlation with patients' decisions for DBS ($p<0.001$). In this study, the participants' age range was 53 to 70 years old (median age = 63), and age was positively correlated with choosing the DBS treatment option. In this study, the participants valued DBS education as a useful tool to learn about DBS and to make an informed decision.

Knoop and colleagues (2017) aimed to learn if patients' expectations from DBS were met and attempted to identify the gaps in patient education. This study concluded that patient education should start early in the preoperative process and discussion of realistic expectations

from DBS should be a part of DBS education (Knoop et al., 2017). The study participants received education from a DBS neurologist and fewer (61%) from a neurosurgeon, without a specific guideline or content. A considerable percentage of patients did not feel adequately prepared for the DBS procedure. This study suggested that a structured and multidisciplinary team approach to DBS patient education before surgery improves patients' experiences and satisfaction with DBS surgery outcomes. The findings by Knoop and colleagues (2017) underline the gaps in DBS education among participants and how this gap might lead to unrealistic DBS expectations among the recipients. The findings from both studies similarly highlight the significance of implementing the DBS education program because, currently there is not a uniform DBS education program in place.

Castrioto et al. (2011) looked at the 10-year motor outcome in PD patients after subthalamic nucleus DBS (STN-DBS). Clinical assessment was conducted according to the Core Assessment Program for Surgical Interventional Therapies in Parkinson's disease protocol. Eighteen DBS recipients were videotaped at baseline and one, five, and ten years after surgery. An independent rater blinded to stimulation or medication treatment scored the10-year video assessments of these DBS recipients at ten years post-surgery. This study provided evidence that DBS significantly improved motor symptoms (p=0.007). In addition, the findings of this study showed that the PD motor improvement was sustained at least 10 years after DBS implantation, despite the natural history of PD and the progression of symptoms over time (Castrioto et al., 2011). Therefore, the long-term DBS benefit reflects the time that the DBS recipients need to manage DBS therapy at home, and the data support the benefit of a DBS education program as a critical element for better patient outcomes.

Surucu, Baumann-Vogel, Uhl, Imbach, and Baumann (2013) compared the best medical therapy for the treatment of PD symptoms. This study prospectively analyzed 14 consecutive Parkinson's patients who underwent STN-DBS. In eight of these patients (>60%), PD symptoms decreased markedly, and the researchers concluded that DBS combined with best medical therapy is more effective than optimal medical therapy alone (Surucu et al., 2013).

Effective symptom management can significantly affect a patient's quality of life (QOL). Dogru Huzmeli and Yilmaz (2018) assessed QOL after DBS in 19 PD patients (12 male, 7 female), with over five years of disease duration by using the RAND 36-Item Health Survey. The study showed that QOL improved after DBS surgery among 51% of patients, while 47% reported stable QOL and 2% reported worsening. The QOL improved with DBS in both male and female recipients but was overall higher in female patients.

One possible factor that affects patients' QOL after DBS implantation is the development of complications, including various types of infection. DBS hardware infection is the subject of a study by Abode-Iyamah et al. (2018), which estimated the rate to be as high as 20% among recipients. DBS infection is a costly and severe complication that could potentially be tackled with improved DBS education. Some studies have shown that patient education decreases the risk of post-surgical infection rates and improves the patient outcome (McDonald, Page, Beringer, Wasiak, & Sprowson, 2014; Jia et al., Hongwei, Fangang, et al., 2016; Dinkelbach, Moller, Witt, et al., 2017; Knoop, Kadish, Hager, et al., 2017).

In conclusion, the reviewed studies indicated that lack of knowledge increased the rates of complications (infection, breakage of wires or leads, inadequate preparation for DBS care and monitoring at home). Moreover, education and training programs were effective in increasing DBS knowledge. However, these studies were based on different isolated topics (DBS device,

battery replacement, promoting DBS placement), mostly retrospective, and not comprehensive. Furthermore, the personnel providing education were physicians with a medically oriented perspective, without considering psychosocial issues or need for supportive needs after DBS placement. Most importantly, caregivers were not included in the studies. Therefore, this project will examine whether the implementation of an Advanced Practice Registered Nurse-led comprehensive DBS Education-Based Intervention program (DBS-EBI) will increase DBS knowledge, compared with baseline, immediately after the DBS-EBI, and two weeks after DBS-EBI.

METHODOLOGY

Design

This was a single arm study to examine changes in knowledge and satisfaction level among patients and caregivers before and after DBS-EBI. This QI project was conducted over 9 weeks between January10th to March16th, 2020. Patients and caregivers completed a 1) DBS Knowledge Evaluation Form at baseline (T1), immediately after (T2), and two weeks after DBS-EBI (T3) and 2) DBS-EBI Program Evaluation Form. The project received exempt status from UCLA-IRB on Jan 2nd, 2020 and the sponsor institution honored the exempt status. The project strictly followed ethical guidelines.

Setting & Sample

The project was implemented in a large university-affiliated Medical Center in the metropolitan area in the southwestern United States between January10th to March 16th, 2020. Ten patients and 12 caregivers were recruited from the Medical Center Department of

Neuroscience. This department sees about 100 new patients per year for Parkinson's and Essential Tremors, with approximately 1,000 visits per year. The patients and caregivers were eligible if 1) patients had a diagnosis of PD or ET, based on ICD diagnostic codes, 2) were considering DBS Therapy within 3 to 4 months, 3) willing to participate in the DBS-EBI, and 4) willing to complete study procedures. All ten patients had a routine cognitive evaluation conducted by trained clinical psychologists prior to participating in the DBS-EBI project and fluent in the English language. The enrollment window was three weeks shorter than planned due to the COVID-19 pandemic.

Sample Size

A total of ten eligible patients with the diagnosis of PD or ET (7 PD, 2 ET and, 1 both PD & ET) and 12 caregivers were enrolled in this QI pilot project. The goal was to recruit 30 participants but the open enrollment period was three weeks shorter than planned due to the COVID-19 pandemic.

Screening, Recruitment

The principal investigator (PI) received the names of all DBS candidates from the DBS Center neurosurgeons and neurologists, who were scheduled for DBS placements in the next few weeks. The PI contacted the eligible patients and caregivers about the next scheduled neurology or neurosurgery appointment. The PI introduced the DBS-EBI project and asked if the patient and caregiver were willing to participate in the project. Participants who opted in were scheduled to participate in the DBS-EBI during a 60-minute session after their next scheduled neurology or neurosurgery appointment.

Enrollment

Ten eligible patients and 12 caregivers enrolled and completed the DBS-EBI program after their scheduled appointments (two patients had two caregivers). The PI provided a detailed explanation of the DBS-EBI project and the materials used to evaluate their knowledge and their thoughts about the DBS-EBI. The participants signed the enrollment agreement before taking part in the DBS-EBI program. To reduce the participant burden, participants were mailed a $20 gift card after they completed the DBS-EBI surveys.

DBS-EBI

The DBS-EBI was developed by the PI, who is an advanced practice registered nurse and a doctoral nursing practice candidate (DNPc) that works with DBS patients in the past 20 years. She coordinates the overall care of these patients, including the pre and post-surgery appointments, the device programming, education of caregivers in DBS, and DBS support group.

The DNPc provided the DBS-EBI (face to face) that takes approximately 60 minutes. The study participants received an invitation letter (Appendices), and the DBS-EBI includes a DBS Education Pamphlet (Appendices) and a 15-minute PowerPoint presentation (Appendices). The patient and caregivers completed the Knowledge Evaluation Form (Appendices) before (T1), immediately after (T2), and about two weeks after (T3). The content includes information on 1) DBS device, 2) Treatment Options, 3) Risks, Prevention, and Management of Complications, 4) pre-operative and post-operative care, 5) follow-up appointments, 6) Education & Psychosocial Support, and 7) Safety. The DBS-EBI occurred in a quiet and private area in the DBS- clinic center. The DNPc received a site permit from the Neuroscience Chair and Clinic Management to

implement the DBS-EBI project in the DBS Center and used personal time to conduct this project.

Data Collection & Measures

Surveys were conducted at baseline (T1), immediately after DBS-EBI (T2) and 2 weeks after the DBS-EBI (T3). Surveys were linked using study IDs and the code key was only accessible to the PI. Copies of all surveys items are provided in Appendices. All survey items were reviewed by a group of ten, multidisciplinary DBS- care providers team (DBS-CP), who endorsed their use and also approved the final DBS-EBI content, including the Patient Education Pamphlet and Patient Education PowerPoint, prior to study initiation.

Demographics Form.

Patients were asked to provide their age, sex, ethnicity, primary language, education level, diagnosis, and year of diagnosis. Caregivers were asked to provide their age, language, ethnicity, primary language, education level, and relationship to patients. This survey was conducted only at baseline (T1).

DBS Health Care Provider (DBS-CP) Evaluation Form

The DBS-CP evaluation form consisted of 6 survey items that asked participating health care providers, who reviewed DBS-EBI materials, to rate the extent to which they agreed or disagreed (using a 5-point Likert scale) with the following statements: 1) *Content was relevant; 2) Information was well organized; 3) The PowerPoint presentation was helpful; 4) The*

educational pamphlet was clear; 5) The checklist was useful; and 6) Overall satisfaction with DBS education. This survey was conducted before study implementation.

DBS-EBI Knowledge Evaluation Form

The DBS-EBI Knowledge Evaluation Form consisted of 20 True and False items pertaining to DBS knowledge. Four items were included for each of the following topics: 1) signs and symptoms indicating infection; 2) signs and symptoms that would require a call to the surgeon's office or 911; 3) situations that should prompt a call to the DBS Neurology Clinic; 4) recommended home care after DBS surgery; and 5) actions to enhance home safety after DBS surgery. Although the sequence of the survey items varied, participants received the same Knowledge Evaluation survey items at baseline, immediately after DBS-EBI and 2 weeks after DBS-EBI (T1, T2 and T3). There are two parallel forms, one used at T1 and T3 and the other used at T2. Participants were given 1 point for each correct item up to a maximum of 20 points. This survey took about 10 minutes to complete. If participants were not able to attend a follow-up visit two weeks after DBS-EBI, they were provided the option of completing the survey at home and returning it by mail with prepaid postage. Participants who did not mail back their follow-up survey received a reminder phone call.

Caregiver and Patient DBS-EBI Evaluation Form

The Caregiver and Patient Evaluation Form consisted of 10 items that asked participants to rate the extent to which they agreed or disagreed with the following statements: 1) Content was relevant; 2) Information was well organized; 3) The speaker held my interest; 4) The PowerPoint presentation was helpful 5) The educational pamphlet was clear; 6) The checklist

was useful; 7) The DBS education relieved anxiety; 8) Comfortable with having a DBS; 9) I know when to call care provider; and 10) Overall satisfaction with DBS education. There were also three open-ended items to indicate 1) What was the most important thing learned; 2) what could be improved, and 3) other thoughts/comments/feedback. This survey also took about 10 minutes to complete.

Data Analysis

Descriptive statistics (means, standard deviation, frequencies, and percentages) were used to describe participants' demographics, changes in knowledge and satisfaction scores between T1, T2, and T3. Comparison across the three time points were done using the Friedman test, a non-parametric approach to repeated measures. Post hoc pairwise comparisons were done using a Wilcoxon signed ranks test. Non-parametric tests were selected because of the small sample and non-normal distribution. All analyses were conducted using SPSS v. 25, Chicago, IL

RESULTS

Patient demographics were seven patients with Parkinson's Disease (PD), two with Essential Tremors (ET), and one with both PD and ET (age 58.8 ± 17.28 years); 4 female; time since diagnosis 6.2 ± 8.9 years) and caregivers (n=12, 58.0 ± 15.3 years; 10 female). The majority of patients had college education (BS/BA, MD, PhD). Caregivers (n=12; 58.0 ± 15.3; 10 female) who were spouse (n=3), significant others (n=2), siblings (n=3), parents (n=3), or son and daughter (n=1) (Table 1).

Knowledge

Patients had increased in knowledge (χ^2 df=2, 13.2, p = 0.001), with scores at T2 (17.6 ± 2.8) were significantly higher than T1 (14 ± 5.1, p = 0.007) and were also significantly higher at T3 (18.4 ± 1.5, p = 0.01) than T2 (Table 2). Many of the patients did not know (false choice) about signs and symptoms (nausea, vomiting) indicating infection, when to call provider to reports signs and symptoms, and actions to promote home safety after DBS surgery.

Caregivers (n = 12; 58.0 ± 15.33 years) also had increased knowledge over the three time- points (χ^2 df=2, = 10.82, p = .004), with scores at T2 (17.7 ± 1.6) significantly higher than T1 (15.8 ± 3.2, p = 0.007) and were also higher at T3 (18.8 ± 1.2, p = 0.05) than T2. Many of the patients did not know (false choice) about reporting signs and symptoms and when to call providers or 911 (Table 2).

Satisfaction

The majority of patients (70-90%) thought that the DBS-EBI content is relevant, information is well organized, power point presentation is helpful, education pamphlet is clear, checklist is useful, and they were satisfied with DBS Education. Patients (33%) reported that the DBS-EBI was helpful, educational, and had good information, and gave positive comments (60%) on the DBS-EBI power point presentation and the pamphlet that was given for reference at home. Patients also reported that the most important information were related to before and after surgery (57.1%) and others stated (42.9%) the process and procedures, personal concerns, and symptoms were important (Table 3). Other comments made were; they liked the terms, dictionary, and checklist, and they expressed concern such as *"They will cut all my hair off. The device is really big."*

Caregivers found the DBS-EBI was helpful (67.7%), both educational and had good information (50%), and gave positive comments (60%) on the DBS-EBI power point presentation and the pamphlet that was given for reference at home. An example of a positive response was *"I don't think there need to be any improvements in the presentation or written materials. I think the presentation, as well as the written materials are easy to understand"* (Table 4).

Caregivers also reported that the most important information were related to surgery before and after (66.7%) and precautions to minimize risk for infection (50%) (Table 3). Another important information that caregivers thought was important was "to put handbar in the bathroom, open a door slowly, avoid the path to fall" and "realized that it would be easy for the patient to fall". They also realized how important it is to *"pay more attention to his surgical site and his suture area."* The other thoughts, comments, and feedback that caregivers provided were "very helpful information." They were more aware of infection, and they worry that *"it may be hard to contact surgeons,"* during off hours. For example, *"It kind of scared my mom. I have a huge fear of infection now. But any info is extremely helpful in this type of surgery. I'm having a hard time reaching neurosurgery team w/ specific questions about surgery."* Examples of grateful comments were, *"I see how much you care for your patients,"* and *"So very thankful for the whole process and fabulous team!"* (Table 4).

Discussion

This study provided evidence that the innovative Advanced Practice Registered Nurse-led comprehensive DBS-EBI improved patients and caregivers' knowledge on DBS care that were sustained after two weeks. Knoop, et al (2017) reported that patients were seeking DBS

education on their own through internet sources, and consequently the physicians provided information that was most likely focused on the DBS device and its effects to minimize motor symptoms in PD; some patients however, reported that they did not feel adequately prepared for surgery. In addition, the conclusion indicated a recommendation for a structured and multidisciplinary team approach to provide DBS education before surgery may improve patient experience and satisfaction with DBS. Another study in Germany examined the effects of a DBS education, and found that patients found it very helpful when they were making decisions for accepting the DBS treatment option (Dinkelbach, 2017). However, this study did not indicate the content of the DBS education which was most likely focused on promoting the surgical device, typically recommended by physicians. To date, there are no other studies conducted in the U.S that reported on a comprehensive DBS education that involved not only patients but also caregivers. The most innovative aspect of the APRN led DBS-EBI was that the focus was not only on the functionalities of the medical or surgical device, but also on what they need to know about DBS preparation before, and care after surgery. In addition, the DBS-EBI included information that patients thought were very important and helpful to know about signs and symptoms of complications, safety to minimize risks of falls, and when to call the medical provider or "911."

This quality improvement project provided evidence to support the DBS-education for patients and caregivers that would promote long-term efficacy and safety of DBS-therapy (Cossu & Sensi, 2017). The excellent satisfaction ratings by both patients and caregivers is supportive of developing and standardizing DBS education programs across all DBS-centers. Future studies are recommended to examine whether the effects of the "standardized DBS-EBI" will minimize costs, and improve quality and safety of DBS care among patients and caregivers at home.

Lastly, the DNP DBS-EBI project fulfills the Essential 3: Clinical Scholarship and Analytical Methods for Evidence-Based Practice from the Essentials of Doctoral Education for Advanced Nursing Practice (AACN, 2006).

Limitations

A major limitation of this QI project was the small sample size and being conducted at one large academic center, which may not be representative and could not be generalizable to other settings. The onset of the COVID-19 did not make it possible for further recruitments, thereby limiting the ability to enroll additional patients and caregivers. Therefore, the project will continue when the COVID pandemic ended. Furthermore, the project did not include a control group that were receiving the routine DBS education provided during medical visits in other DBS centers. In addition, there may be confounding variables (age, sex, education, diagnosis) that could not be analyzed due to the small sample size (Verla et al., 2015). Lastly, the participants had private insurance and were fluent in the English language, which also limits generalizability of findings for non-English speaking patients and caregivers, or those without private insurance.

Further Research

Future ongoing DBS-surveillance study to examine long-term benefits of DBS-education on health care costs, quality of DBS-care, safety, patient experience and satisfaction that could lead to improvement in overall quality of life among DBS recipients. Recommendations for studies that would lead to standardization of DBS-EBI in randomized control trials that includes DBS centers nationally and globally. Lastly, because of innovative and widespread use of

technology and social media, future studies may examine the effects of online DBS-EBI that may be more accessible and readily available for patients and caregivers who are making decisions about DBS therapy.

The Doctor of Nursing Practice Role

The Doctor of Nursing Practice (DNP) prepared nurses with the knowledge and leadership skills to develop and lead quality improvement (QI) projects such as DBS-EBI. The QI projects lead to advance care delivery models based on nursing science, through a system thinking methodology and is well-aligned with Essential II: Organizational and Systems Leadership for Quality Improvement and Systems Thinking as well as Essential VI: Inter-professional Collaboration for Improving Patient and Population Health Outcomes (AACN, 2006).

CONCLUSION

The innovative APRN led DBS-EBI project was effective in providing comprehensive information for Parkinson's disease (PD) and Essential Tremors (ET) patients and their caregivers that increased their knowledge and satisfaction with DBS care. The need for DBS education is increasingly more important as the number of DBS-therapy is growing and physicians are increasingly recommending DBS as an effective treatment option for minimizing motor symptoms in PD and ET patients. Given the lack of a standardized DBS education content, guidelines, and protocols, the DBS-EBI could lead to improvement in DBS knowledge, lower complication rates, increase safety, and improve overall health care outcomes in DBS recipients.

Table 1 ***Demographics***

	Patients (n=10)	**Caregivers (n = 12)**
	n (%)	n (%)
Relation to Patient		
Significant other	--	n = 2 (20%)
Spouse	--	n = 3 (30%)
Sibling	--	n = 3 (30%)
Parent	--	n = 3 (30%)
Son/Daughter	--	n = 1 (10%)
Age (years)		
Mean ± SD	56.8 ± 17.3	58.0± 15.3
30 to 59	n = 5 (50%)	n = 6 (60%)
60 to 81	n = 5 (50%)	n = 6 (60%)
Sex		
Male	n = 6 (60%)	n = 2 (16.7%)
Female	n = 4 (40%)	n = 10 (83.3%)
Race/Ethnicity		
Caucasian	n = 8 (80%)	n = 9 (75%)
Asian	n = 2 (20%)	n = 3 (25%)

Language		
English	n = 10 (100%)	n = 12 (100%)
Diagnosis		
Essential Tremor (ET)	n = 1 (10%)	n = 1 (10%)
Parkinson's Disease (PD)	n = 8 (80%)	n = 8 (80%)
Both ET and PD	n = 1 (10%)	n = 1 (10%)
Years Since Diagnosis		
Mean ± SD	8.± 6.2	--
3 to 10	n = 6 (60%)	--
11 to 24	n = 4 (40%)	--
Education		
≤ High School	n = 1 (10%)	n = 3 (25%)
Some college (no degree)	n = 5 (50%)	n = 4 (33%)
BS/BA, PhD/MD/PsyD	n = 4 (40%)	n = 5 (41.7%)

Table 2 ***Knowledge Scores at T1, T2, T3***

	Means ± SD	***p*-value**
Patient		
T1	14.0 ± 5.1	χ^2 (df=2) 13.2, p = 0.001
T2	17.6 ± 2.8	T3 > T2 > T1, p = 0.007
T3	18.4 ± 1.5	
Caregiver		
T1	15.8 ± 3.2	χ^2 (df=2) 10.2, p = 0.004
T2	17.7 ± 1.56	T3 > T2 > T1, p = 0.05
T3	18.8 ± 1.2	

Patients and caregivers had a significant change in knowledge scores at the three timepoints, with improvements in knowledge scores from baseline (T1) to immediately after (T2), that sustained and increase two weeks after DBS-EBI (T3)

Table 3 ***Evaluation of DBS Education-Based Intervention***

	Patients (n=10) n (%)	Caregivers (n-=12) n (%)
Content is relevant		
Strongly Agree	6 (60.0)	--
Somewhat Agree	3 (30.0)	1 (8.3)
Neither	1 (10.0)	11(91.7)
Somewhat Disagree;	--	--
Strongly Disagree	--	--
Information is well organized		
Strongly Agree	8 (80.0)	2 (83.3)
Somewhat Agree	2 (20.0)	10(16.7)
Neither	--	--
Somewhat Disagree	--	--
Strongly Disagree	--	--
Speaker Held My Interest		
Strongly Agree	7 (70.0)	--
Somewhat Agree	2 (20.0)	4 (33.3
Neither	1 (10.0)	1 (8.3)
Somewhat Disagree	--	--
Strongly Disagree	--	--
Power Point presentation is helpful		
Strongly Agree	7 (70.0)	10 (83.3)
Somewhat Agree	2 (20.0)	2 (16.7)
Neither	1 (10.0)	--
Somewhat Disagree	--	--
Strongly Disagree	--	--
Education pamphlet is clear		
Strongly Agree	9 (90.0)	10 (83.3)
Somewhat Agree	1 (10.0)	1 (8.3)
Neither	--	--
Somewhat Disagree	--	--
Strongly Disagree	--	1 (8.3)
Checklist is useful		
Strongly Agree	7 (70.0)	12 (100%)
Somewhat Agree	3 (30.0)	--
Neither	--	--
Somewhat Disagree	--	--
Strongly Disagree	--	--
DBS Education reduced anxiety		
Strongly Agree	6 (60.0)	7 (58.3)
Somewhat Agree	2 (20.0)	4 (33.1)
Neither	2 (20.0)	--
Somewhat Disagree	--	1 (8.3)
Strongly Disagree	--	--
DBS Education increased comfort with DBS		
Strongly Agree	8 (80.0)	8 (66.7)
Somewhat Agree	2 (20.0)	3 (25.0)

Neither	--	1 (8.3)
Somewhat Disagree	--	--
Strongly Disagree	--	--
I know when to call providers		
Strongly Agree	9 (90.0)	10 (83.3)
Somewhat Agree	1 (10.0)	2 (16.7)
Neither	--	--
Somewhat Disagree	--	--
Strongly Disagree	--	--
Overall satisfaction with DBS-EBI		
Strongly Agree	8 (80.0)	10 (83.3)
Somewhat Agree	2 (20.0)	2 (16.7)
Neither	--	--
Somewhat Disagree	--	--
Strongly Disagree	--	--

Table 4 ***Comments, Thoughts, Feedback on DBS Education-Based Intervention***

	Patients (n-=10) **n (%)**	**Caregivers (n=12)** **n (%)**
Most Important Learned		
Pre/post-surgery Process/procedures	4 (57.1)	4 (66.7)
Personal concerns	3 (42.9)	--
Signs & Symptoms	3 (42.9)	--
Infection	3 (42.9)	1 (16.7)
Definition/Organization	2 (28.6)	3 (50.0)
Emergency/Prioritizing	2 (28.6)	--
Safety	2 (28.6)	1 (16.7)
Support	--	1 (16.7)
Power Point & Pamphlet		
Positive response	3 (60.0)	3 (60.0)
Poor print/faded	1 (20.0)	1 (20.0)
True/false questions preferred	1 (20.0)	1 (20.0)
Comments/Thoughts/Feedback		
Helpful	3 (33.3)	4 (66.7)
Educational	3 (33.3)	--
Good Information	3 (33.3)	--
Grateful (team, caring)	--	2 (33.4)
Fear (infection, unable to contact MD	--	2 (33.4)

APPENDICES

Evaluation Materials

Health Care Provider Evaluation of DBS Education Material

ID _____ **Date** _____

Please circle a number from 1 (Strongly Disagree) to 5 (Strongly Agree)

	Strongly Disagree	Somewhat Disagree	Neither	Somewhat Agree	Strongly Agree
Content is relevant	1	2	3	4	5
Information is well organized	1	2	3	4	5
Power Point presentation is helpful	1	2	3	4	5
Education pamphlet is clear	1	2	3	4	5
Checklist is useful	1	2	3	4	5
Overall satisfaction with DBS Education	1	2	3	4	5

What is the most important content in the Education Material?

_____

_____

Is there anything in the Education Material that could be improved? What?

_____

_____

Other thoughts/comments/feedback:

_____

Patient Demographics Form

ID _____ **Date** _____

Age _____

Sex _____

Ethnicity _____

Language _____

Diagnosis _____ Essential Tremor

_____ Parkinson's disease

Time since Diagnosis _____

Education Level

_____ Less than or equal to High School

_____ Some college (no degree)

_____ BS, BA

_____ MS, MA, MBA, etc.

_____ PhD, MD, DNP, PsyD, etc.

Caregiver Demographics Form

ID _____ **Date _____**

Relation to Patient _____

Age _____

Sex _____

Ethnicity _____

Language _____

Education Level

_____ less than or equal to High School

_____ Some college (no degree)

_____ BS, BA

_____ MS, MA, MBA, etc.

_____ PhD, MD, DNP, PsyD, RN

PRE- DBS EDUCATION KNOWLEDGE EVALUATION (T1, T3)

ID _____ Date _____

I. Circle True (T) or False (F) if the signs and symptoms indicate infection

1. T F Fever higher than 101
2. T F Sudden change in memory
3. T F Draining and swelling at the surgical site
4. T F Severe nausea and vomiting

II. Circle True (T) or False (F) if the signs and symptoms indicate calling 911

5. T F Seizure, sudden loss of consciousness
6. T F Mild Headache, nausea, stomach upset
7. T F Sudden change in cognition or confusion
8. T F Sudden change in vision or speech

III. Circle True (T) or False (F) if the situation indicate calling DBS Neurology Clinic

9. T F Schedule Follow-up appointment for DBS Programming
10. T F Have questions regarding billing and payment
11. T F Have questions, Concerns regarding medications or condition
12. T F Have questions, concerns regarding DBS

IV. Circle True (T) or False (F) for actions required at home after DBS surgery

13. T F Take a nice warm bath, or resume swimming and Jacuzzi
14. T F A person needs to be present 24/7 for two weeks after
15. T F Maintain Medication Regimen at home
16. T F Follow post-surgery instructions

V. Circle True (T) or False (F) for actions to promote home safety after DBS surgery

17. T F Use the cane or walker at all times as previously
18. T F Avoid stairs/ladders/reaching and use handrails, shower chair, proper footwear
19. T F Check DBS status at home [Screen shows “ON OK”]
20. T F Participate in DBS Support Group for social and educational support

POST- DBS EDUCATION KNOWLEDGE QUESTIONNAIRE (T2)

ID _____ Date _____

I. Circle True (T) or False (F) if the signs and symptoms indicate infection

1. T F Fever higher than 101
2. T F Sudden change in memory
3. T F Severe nausea and vomiting
4. T F Draining and swelling at surgical site

II. Circle True (T) or False (F) if the signs and symptoms indicate calling 911

5 T F Seizure, sudden loss of consciousness
6. T F Mild Headache, nausea, stomach upset
7. T F Sudden change in vision or speech
8. T F Sudden change in cognition or confusion

III. Circle True (T) or False (F) if the situation indicate calling DBS Neurology Clinic

9. T F Schedule Follow-up appointment for DBS Programming
10. T F Have questions regarding billing and payment
11. T F Have questions, Concerns regarding medications or condition
12. T F Have questions, concerns regarding DBS

IV. Circle True (T) or False (F) for actions required at home after DBS surgery

13. T F Take a nice warm bath, or resume swimming and Jacuzzi
14. T F A person needs to be present 24/7 for two weeks after
15. T F Follow post-surgery instructions
16. T F Maintain Medication Regiment at home

V. Circle True (T) or False (F) for actions to promote home safety after DBS surgery

17. T F Use the cane or walker at all times are previously
18. T F Avoid stairs/ladders/reaching, use handrails, shower chair, proper footwear
19. T F Check DBS status at home [Screen shows “ON OK”]
20. T F Participate in DBS Support Group for social and educational support

Evaluation of DBS Education- Based Intervention

ID _____ **Date** _____

Please circle a number from 1 (Strongly Disagree) to 5 (Strongly Agree)

	Strongly Disagree	Somewhat Disagree	Neither	Somewhat Agree	Strongly Agree
Content is relevant	1	2	3	4	5
Information is well organized	1	2	3	4	5
Speaker held my interest	1	2	3	4	5
Power Point presentation is helpful	1	2	3	4	5
Education pamphlet is clear	1	2	3	4	5
Checklist is useful	1	2	3	4	5
DBS education reduced my anxiety	1	2	3	4	5
DBS education increased my comfort level with having DBS	1	2	3	4	5
I know when to call care provider	1	2	3	4	5
I am satisfied with DBS education	1	2	3	4	5

What was the most important thing you learned?

_____

_____

Was there anything in the presentation or written materials that you think could be improved? What?

_____

_____

Other thoughts/comments/feedback:

_____

Letter of Invitation to Participate in DBS Education Project

Because you are considering DBS surgery, you and your caregiver are being invited to participate in a one hour DBS Education Project. This project is part of the UCLA Doctorate in Nursing Practice Program.

The DBS Education will include a 15 minutes Power Point presentation and a DBS Education Pamphlet that you may keep for reference. The content will include information related to 1) DBS device, 2) treatment options, 3) risks, prevention, and management of complications, 4) pre-operative and post-operative care, 5) follow-up appointments, 6) ongoing education & psychosocial support, and 7) DBS safety after surgery.

Before the DBS Education starts, you and your caregiver will complete paper and pencil Knowledge Evaluation Form. After the DBS Education, the Knowledge Evaluation Form will once again be completed. This will determine what your knowledge was before and how much you and your caregiver learned after the DBS Education. Lastly, after two weeks from the day you participated in the DBS Education, you and your caregiver will complete the Knowledge Evaluation Form, and a DBS Education Evaluation Form. This will determine how much knowledge you have retained, and whether the DBS Education was effective in the way it was presented, as well, as the benefits you have gained.

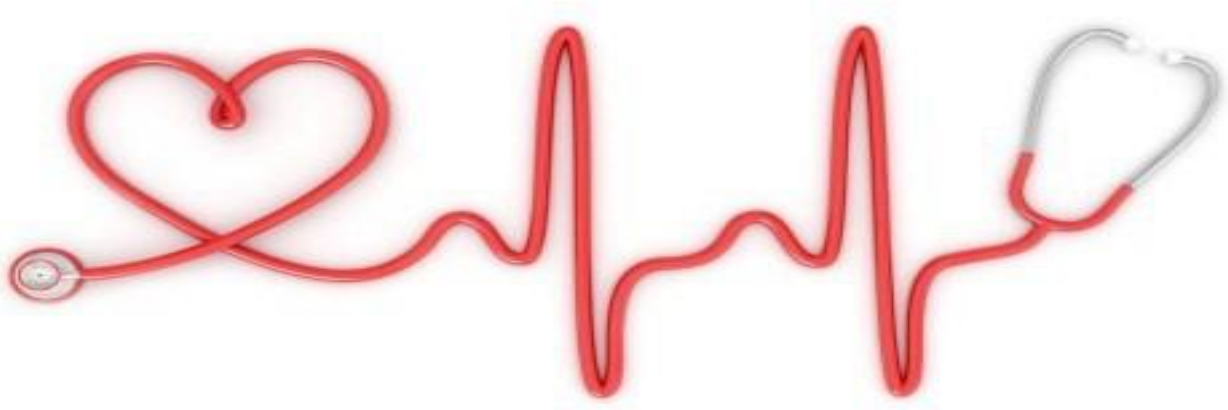
Please discuss with your caregiver and let Nasrin Esnaashari, the DBS Nurse Practitioner via voice message at my phone. Please provide your name and phone number slowly, and clearly. I will return your call to provide additional details and highly appreciate your participation in this patient education project.

Sincerely,

Nasrin Esnaashari, MSN, CNS, CNP, DNPc

Deep Brain Stimulation Therapy Educational Pamphlet for Patients and Caregivers

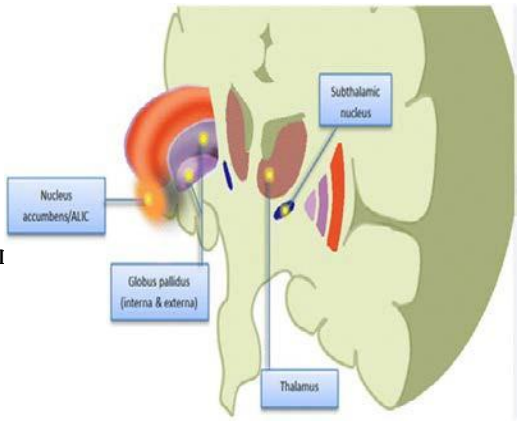
BY: NASRIN ESNAASHARI



This educational pamphlet is a reference for you and your caregivers

TABLE OF CONTENTS

WHAT IS DEEP BRAIN STIMULATOR (DBS)



- A surgically implanted device
- Reduce symptoms in neurological conditions
- May control disabling symptoms
- Does not permanently destroy brain tissue
- Causes minimal damage to any brain tissue
- Surgical placement involves wire insertion (See diagra

WHEN TO CONSIDER DBS TREATMENT

- Medications are not able to control symptoms
- Intolerable medication side effects
- Unpredictable medication effect and benefit

CONSIDERING DBS TREATMENT OPTIONS

- Consult with Movement Disorder Neurologist
- Requires 2-3 appointments for DBS evaluation
  - Neurosurgeon (Surgical Risks)
  - Neurologist pre-surgery (Medication Response Assessment)
  - Clinical psychologist (Emotional, Social, Cognitive Assessment)
  - Pre-surgery Evaluation
  - Chest X-ray, Brain MRI, EKG (heart rhythm)
  - Blood tests (complete blood count, kidney-liver function, clotting tests)
  - Blood pregnancy test (female in childbearing age)
  - DBS Support-Support Group (DBS patients/caregiver for education and social support)
- DBS Surgery (FDA APPROVED)
  - Lead placement in Brain
  - Pulse generator (battery) unit placement in Chest

    DBS Surgical Option
  - Awake with Sedation (communicating with surgeon during surgery)
  - General anesthesia (MRI guided Sleep DBS)

FACTORS TO CONSIDER

- Process (3-4 months prior to surgery)
- First 3 months after surgery (every 2 to 3 weeks)
- May be emotionally, physically, and time consuming
- Does not stop progression
- Control symptoms (tremors, stiffness, rigidity, abnormal movements)
- May improve mood, energy level, general sense of wellbeing
- Ask who will be the DBS Programmer and contact information
- Important to keep appointments as scheduled to minimize delay

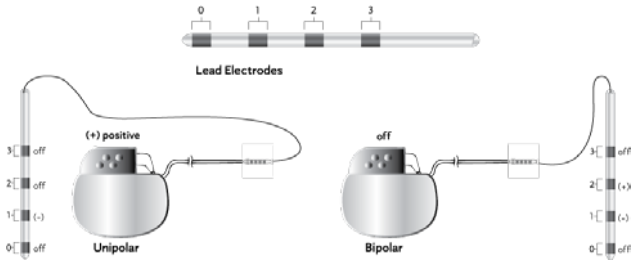
DBS DEVICE & FUNCTION

- DBS battery (powered computer unit)
- Programming (DBS activation, stimulator settings)
- Battery Options:

- Non-rechargeable, change every 3-4 years)
- Rechargeable (daily recharge, replace every 9 years)

Different DBS Battery

DBS Lead Tips



DBS Leads & Battery

PATIENT CONTROLLER UNIT

Controller Unit

Controller Unit Box

DBS Features

iPad / iPhone Programmer (Boston)

IPad Programmer (Medtronic)

FEATU.ES

1. Turns DBS ON or OFF
2. Check Key
3. Power/Backlight
4. Selection key
5. Navigator Key

** Check DBS-status at home weekly;

RISKS AND COMPLICATIONS OF DBS

- Serious or permanent disability (less than 1% risk)
  - Stroke or bleeding in brain during surgery (up to 2-3% risk)
  - May experience stroke-like symptoms

    (Weakness, numbness, blurred vision, slurred speech)
- Temporary or reversible complications (Infection at surgery sites; 20%)
  - Administration of antibiotics during surgery.
  - Removal of the electrode, connecting wire, and/or DBS battery
  - Report the following symptoms immediately after surgery:
    - **FEVER (higher than 101)**
    - **SWELLING, DRAINAGE AT INCISION SITE**
    - **CHILLS, VOMITING, SEVERE HEADACHE, SEIZURE**
- Pain commonly experienced (Mild headaches, surgery site pain)
- Potential Risks Must Be Reported
  - Mood changes (confusion and/or hallucinations)
  - Mental changes (memory, thought processes, mental processes)
  - Worsening extra body movements (Dyskinesia)
  - Headache, dizziness, tingling face or limb

MALFUNCTIONING DBS

- Lead migration (electrode moved away from the optimal target site)
- Fracture, disconnection, or damage of the connecting wire
- Malfunction or injury to the DBS battery
- Problems cannot be predicted or prevented

WHAT TO DO BEFORE SURGERY

- Write down the address, phone numbers, and parking instructions
- Arrive a day early if coming from out of town (stay near the hospital
- Call DBS center for lodging recommendations (hotel discounts, etc.)
- Confirm medication instructions (routine, Pre-Op) prior to surgery
- Learn and practice relaxation techniques (Meditation, Mindful breathing, Listening to music)

DBS-SUPPORT GROUP

- Ongoing monthly patient/caregiver support and education (3rd. Thursday each month 10:30 to 12:00 Noon)
- Special topics presented by healthcare providers (MD, PT, OT, Psychologist and others)
- Patient, family, caregivers and friends are welcome
- Meet and connect with DBS patients and caregivers
- Important information about DBS (benefits, limitations, expectations, etc.)
- Highly important to participate in Support Group before, after DBS surgery

PACKING LIST FOR HOSPITAL

- All medicines (original labeled bottles) and a list of medications and times
- Names and phone numbers of emergency contacts
- Personal items (reading glasses, hearing aids, cane, etc.)

THE NIGHT BEFORE SURGERY

- Get a good night sleep
- Follow the instructions on your medication schedule and fasting for surgery
- Give yourself sufficient time to get there on time

DBS SURGERY PART I

- Follow the surgery instructions from the night before
- Arrive one hour before your surgery time to admitting office
- Change clothes for surgery and care of any bathroom needs
- Check blood pressure, IV (intravenous line) placement, shaving head
- Anesthesiologist for sedation (to relax or sleep)
- Neurosurgeon numb area for head frame placement
- MRI or a CAT scan to guide lead placement in brain
- Neurosurgeon, nurses, anesthesiologist are in room during surrey
- A dime-sized hole is drilled in the skull (under sedation or sleep-DBS)
- Closely monitored for one to two hours in recovery room after surgery
- Hospital stay for 24 hours (with awake-DBS), or longer (with sleep-DBS) after surgery
- After discharge, continue pre-surgery medication according to instructions

DBS SURGERY PART II

- Follow the surgery instructions from the night before
- DBS-battery placement (usually one week later)
- The brain lead wires are connected to DBS-battery
- Discharge home same day with personal hand-held patient controller unit
- Follow post procedure intrusions for medication and wound check appointment

AFTER SURGERY

- Report complications (infection, stroke, seizures etc.); CALL neurosurgeon office
- Call for DBS-programming appointment to activate DBS system
- Call for wound check appointment and sutures or staples removal (10 to 14 days after surgery)
- Expect Mild pain, take medication as instructed

- Expect to receive a wallet-size card DBS- identification card in the mail (must carry at all time)

CALL 911 IMMEDIATELY

- **Loss Of Vision, Sudden Severe Headache, Sever Vomiting, Seizures**
- **Stroke Like Symptoms (Loss Of Arm/Legs Function, Weakness In One Side Of Body)**
- **Choking Or Swallowing Difficulty**

INFECTION PREVENTION

- Follow discharge instructions and call surgeons office for questions
  - **Incision, keep stitches clean & dry; no scratching/touching or pressure on incision**
  - **Report Redness, Swelling, Fever higher than 101, incision drainage**
  - **Remember; complete or partial DBS-removal after Infection**
- Take medications per instruction
- Shower OK; NO swimming, bathtub or Jacuzzi (**40 days after surgery)**
- Wash hands frequently; wash hands after handling pets
- Change pillow cases & sheets daily have clean bedding
- Stay away from people with Flu or infection diseases such Pneumonia
- May use washable wigs, hats; wash them after use

DBS PROGRAMMING

- DBS Programming (few days after battery-placement; every 2 weeks)

  Visit #1: DBS-Settings & medication adjustment (2 hours)
  - Hold PD medications for 8-10 hours
  - Bring medications in original bottles

  Visit #2: DBS & medication adjustment (1 hour)

  Visit #3: Refine DBS-programming & medication (1 hour)

  Visit #4: Optimization of DBS-settings and medication schedule (1 hour)

  Visit #5: see neurologist for post DBS-evaluation (30 minutes)
- Symptom Monitoring
  - Tremor, rigidity, bradykinesia, dyskinesia/dystonia
  - Side effects (tingling, muscle cramping, pulling, electrical shock-like sensation)
- DBS battery life
  - Non-rechargeable (2 to 5 years)
  - Re-chargeable is 9 years (needs daily charge)

- DBS-battery replacement (same settings)
- DBS-can turns off in Magnetic field
- Turn on DBS device with hand-held patient controller
- Keep hand-held patient controller unit (when travelling)

MRI, CT SCAN, X-RAY, MAMOGRAM AND CARDIAC PACEMAKER AFTER DBS

- Notify the technician before/during procedure about having DBS
- Must have prescriptions from DBS-surgeon for any MRI & special MRI equipment
- Turn DBS off when indicated for CAT scans, DAT/SPECT, X-rays, PET, Ultrasound
- Must **NOT have Diathermy** (a deep heat treatment)
- If cardiac pacemaker is necessary, placement must be 10 inches away from DBS-battery
- If mammogram is necessary-alert technician **NO compression of DBS-battery or wires**

OTHER SAFETY TIPS

- Show DBS-Medical Card to airport officer before entering security lines
- Have your "hand-held controller" readily available at all times
- Household electric devices are safe to use (vacuum cleaner, radio, computer, microwave)
- Small power tools are safe to use (Drills, saws, yard tools)

FINAL CHECKLIST

- ✓ **NO MRI unless approved DBS provider**
- ✓ **Never have diathermy**
- ✓ Check with DBS Provider for any surgical procedures
- ✓ To minimize unintentional turn off of DBS device
  - ✓ Stay away from magnetic detectors
  - ✓ Walk as close to center of entrance to stores
  - ✓ Remove unnecessary magnets in your home
  - ✓ Stand away from the microwave when in use
- ✓ Security Check in at airports
  - ✓ Show wallet-size medical card
  - ✓ Wear medical-alert bracelet (DBS device)
  - ✓ Carry patient controller & readily available
- ✓ No lithotripsy (for kidney stones)
- ✓ No electrical or magnetic device near BDS-battery
- ✓ Contact DBS centers,(Medtronic: **1-800-510-6735,**

  Abbott: 1-800-727-7846, Boston Scientific: 1-833-327-4636)
- ✓ Take medication on time and do mild exercise daily
- ✓ Participate in DBS-support group
- ✓ See Medical terms in Table for additional information
- ✓ **We are here to help with your DBS-journey**
- ✓ **Do not hesitate to call for questions, concerns, etc.**

TERMS AND MEDICAL JARGONS

Bradykinesia	Slowed movement (walking, moving around)
Bilateral	On both sides
Computed axial tomography (CAT) scan	Detailed pictures of the brain and other body regions, compatible with DBS
Connecting wire	Connects the brain electrode to the DBS-battery source
Deep brain stimulator (DBS)	A surgically implanted device with leads and wires; connected to pacemaker (DBS-battery)
Dyskinesia	Involuntary, irregular, rapid, dance-like movements
Dystonia	Involuntary, irregular, slow, sustained contraction of muscles
Diathermy	Ultrasound heat-therapy by applying a heated coil to the skin or body **CONTRAINDICATED WITH DBS**
Electrocautery	Surgical technique to stop bleeding **POTENTIAL RISK WITH DBS**
Essential tremor	AKA familial tremor, affects hands, head and voice
Frame	A large metal ring attached to the scalp during DBS surgery
Globus pallidus internus (GPi)	A region of the brain associated with motor pathways and movement
Implantable pulse generator (IPG)	DBS Battery (DBS-battery), similar to heart pacemakers Surgically implanted under skin of upper chest

Magnetic resonance imaging (MRI)	Detailed pictures of the brain or other body regions MRI is used during DBS surgery **MRI after DBS only with neurosurgeon approval**
Movement disorders neurologist	Neurologist with specific training to treat PD and other movement disorders
Neuropsychologist	A clinical psychologist who evaluate DBS-candidate for memory and emotional status
Neuropsychological tests	A series of tests that measure various aspects of memory and thinking
Neurosurgeon	A physician who specializes in surgery of the nervous system
Non-motor symptoms	Symptoms of PD that do not relate to movement (mood changes, sweating, drooling and depression)
"Off" time	A period of time when symptoms like tremor, bradykinesia, and rigidity is present
"On" time	A period of time when the motor function is optimal
Rigidity	Muscle stiffness or an increase in muscle tone
Subthalamic nucleus (STN)	A specific region of the brain associated with motor pathways and movement
Tremor	A rhythmic shaking, involuntary movement of arms, legs or the whole body
Unified Parkinson's disease Rating Scale (UPDRS)	Measurement of Carbidopa effect in PD and used for pre-evaluation of DBS treatment option

DBS-EBI Education PowerPoint Slides

Learning about Deep Brain Stimulation (DBS)

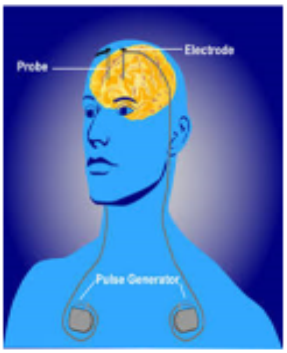
NASRIN ESNAASHARI, MSN, CCRN, CNS/CNP

UNIVERSITY OF CALIFORNIA LOS ANGELES

What Is Deep Brain Stimulator (DBS)?

IMPLANTED LEADS IN CERTAIN AREAS OF THE BRAIN.

IS APPROVED BY THE FOOD AND DRUG ADMINISTRATION (FDA).



Electrodes (leads) are implanted in a specific area of the brain to deliver electrical impulses

The deep brain stimulation offers relief from the tremors, rigidity, slowness & stiffness

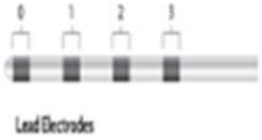
DBS improves motor symptoms.

DBS does not help with

depression or anxiety

DBS-Device

DBS LEADS AND DBS BATTERY (IPG)



Lead Electrodes

The lead is just over a millimeter in diameter

Almost the size of angel hair pasta

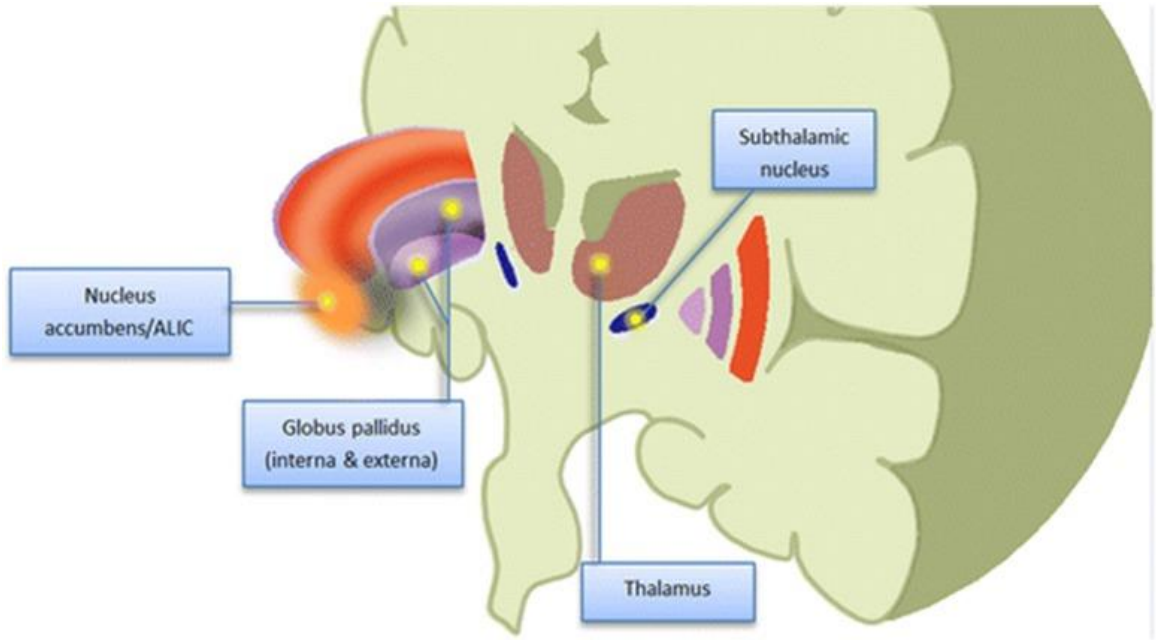
Implanted in a specific part of the brain

Usually on both side of the brain (bilaterally)

Attached to connector-wires that run under the scalp

Plugged into a pulse generator called DBS-battery or IPG

The surgical targets for DBS placement



After DBS surgery you must immediately report the following signs & symptoms to your surgeon

SIGNS OF INFECTION

- Fever over 101
- Sever chills
- Nausea & vomiting
- Drainage from incision
- Redness or swelling around incisions

OTHER SIGNS TO REPORT

- Seizure
- Double vision
- Dizziness or disorientation
- Speech difficulty
- Hallucination or psychosis
- Change in balance

How to prevent infection after DBS surgery?

- Frequent hand washing
- Change pillow case daily
- Avoid being around sick people
- Appointment with surgeon for wound check 2 to 3 days after surgery
- Shower according to post surgery instructions
- Post op appointment with neurology team
- Do not touch or itch your incisions
- Wash hands after handling pets

How does it look after surgery?

How does it look few months later

- May have one or two batteries
- Similar to cardiac pacemaker
- No wire part is expose
- The scar incisions are often hidden under the hair
- Two months after DBS-surgery, can swim and exercise

How to prevent infection after DBS surgery?

- Frequent hand washing
- Change pillow case daily
- Avoid being around sick people
- Appointment with surgeon for wound check 2 to 3 days after surgery
- Shower according to post surgery instructions
- Post op appointment with neurology team
- Do not touch or itch your incisions
- Wash hands after handling pets

Patient Access Control

HOW IT WORKS?

- Turns DBS ON/OFF
- Should carry when travelling
- Easy to operate
- To check DBS-Setting at home
- Shows sign when DBS-battery is low

DBS-PATIENT PROGRAMMER

WHAT DO THE BUTTONS DO?

Your manual explains the symbols displayed on the screen. The illustration shows the main buttons on the DBS Patient Programmer for Activa neurostimulators

1- Turn DBS ON or OFF.
2-Check status of neurostimulator battery.
3.Press up or down arrows for menu options. Press left or right arrows to see more choices.
4.Increase or decrease therapy settings if provided by your physician.
5.Turn programmer on and off.

DBS-programming

DBS-programming

- DBS is turned "ON" by a trained medical professional
- You need 3 to 4 visits to optimize the DBS-settings
- You might experience tingling, mild pressure or pulling during the programming session
- First visit: Hold PD meds for 8 hours before programming
- Bring your PD medications in the original bottle to the first programming visit
- The first DBS-programming might take 2 hours or more
- Bring your "DBS-Patient programmer" with you
- You can review your concerns and ask your questions in this visit

DBS check list before DBS-surgery

- ✓2 to 3 visits with neurologist to confirm DBS-benefit
- ✓Define DBS-expectations since DBS only improves motor-symptom control
- ✓Participate at the DBS-support groups with caregivers and family members
- ✓Learn about DBS, ask question and connect with other DBS-patients

DBS check list after DBS-surgery

- ✓Take your medications as been instructed
- ✓Meticulous personal hygiene and frequent handwashing
- ✓Make appointment for wound check
- ✓Report signs or symptoms of infection and Seizure or vision changes
- ✓Make appointment for DBS- programming
- ✓Learn to use your DBS-access control

Table of Evidence

Author, Year	**Purpose**	**Sample & Setting**	**Methods** **Design** **Interventions** **Measures**	**Results**	**Discussion, Interpretation, Limitation of Findings**
Dinkelbach, L., Moller, B., Witt, K., Schnitzler, A., & Sudmeyer, M. (2017). How to improve patient education on deep brain stimulation in Parkinson's disease: The CARE Monitor study. *BioMedical*	The aim of the study was to improve patient education for DBS and to identify key factors that influence the patients' decision to undergo further diagnostic assessment at a	264 patients' files; homogenous, all Caucasian sample. Ages 53 to 70 years old with PD in a single German DBS Center	Retrospective data analysis with Mann Whitney & Chi-Square tests; DBS education (using the electronic preselection tool STIMULUS) positively correlated with the decision for accepting DBS-treatment option. Patients received 26 pages of DBS educational material and a 4- minute digital video disc	Study findings revealed that DBS education positively correlated with patient decision for accepting the DBS treatment option.78.4% of DBS candidates said the educational material was very helpful (p<0.001). .	Adequate patient education is fundamental to allay patients' aversion to DBS. DBS education is a useful tool for DBS acceptance among suitable candidates. Lack of control group, or randomization and heterogeneous of study samples. Large variables among the referral sources and educators, and lack of quality of life measurement (PDQ-39). Age, severity of symptoms, and medication side effects

Center Neurology, *17*(36), 1-6. doi:10.1186/s12883-017-0820-7	specialized DBS-center.		(DVD) of DBS procedure.		also positively correlated to decision for DBS. Homogenous, all Caucasian German group poses limitations to the generalization of study findings.
Knoop, C. D., Kadish, R., Hager, K., Park, M. C., Loprinzi, P. D., & LaFaver, K. (2017). Bridging the gaps in patient education for DBS surgery in Parkinson's disease. *Parkinson's Disease*, *2017*(9360354), 1-6. doi:10.1155/	The purpose of this study was to find out if patient expectations of DBS were met and to identify the gap in DBS patient education.	29 post DBS patients' questionnaires ; sample participants were 36 to 86 years old, in a single academic DBS center; 21 male & 8 female.	Retrospective review of 52 PD patients who had DBS surgery between 2007 and 2014. 52 questionnaires mailed, 32 were returned, and 29 were included in the analysis.	100% of patients agreed at least part of their DBS expectations were met. 32.1% strongly agreed that DBS education was adequate and 46.4% agreed. 3.6% strongly disagreed to have received adequate DBS education prior to surgery. Only 28% of DBS-eligible patients, consider DBS treatment, due to lack of DBS-knowledge and understanding of the benefits. Frequently, patients sought education on their own. 46% reporting	Study findings demonstrate that patients' expectations of DBS surgery in PD were at least partially met. There was a considerable percentage of patients who did not feel adequately prepared for the procedure. A structured, multidisciplinary team approach in educating PD patients throughout the different stages of DBS surgery may be helpful in optimizing patients' experience and satisfaction with surgery outcomes. Although, in general, DBS patients are happy with

2017/9360354				education from Internet sources.	DBS results, there is opportunity for preoperative DBS education. The small sample size and lack of diversity limits generalization of findings. The reliability or validity of survey instrument was not evaluated.
Castrioto, A., Lozano, A. M., Poon, Y. Y., Lang, A. E., Fallis, M., & Moro, E. (2011). Ten-year outcome of subthalamic stimulation in Parkinson disease: A blinded evaluation.	The purpose of this study was to assess the 10-year post-DBS motor outcome in PD patients.	18 patients (12 men and 6 women) at the Movement Disorders Centre in Toronto Western Hospital, University of Toronto	Patients were videotaped at baseline, then at 1, 5, and 10 years after DBS surgery. An independent rater blinded to stimulation or medication treatment assessed and scored the video assessments of these DBS recipients at 10 years post-surgery,	Total motor score improvement with DBS was documented on 100% of participant cases. Tremor control was sustained 85% - 87.5% and bradykinesia was controlled on 23% of participants. Except for 2 patients with device infection, other symptoms such as	Despite the natural history of PD progression, post-DBS motor improvement was sustained at the 10-year benchmark among the 18 participants. This is a Class III evidence-based study, which supports long-term benefit of DBS in motor symptom control (p=.007). Small sample size, along with lack of a control group

Archives of Neurology, *68*(12), 1550-1556. doi:10.1001/archneurol.2011.182			by utilizing the Core Assessment Program for Surgical Interventional Therapies in Parkinson's Disease protocol	cognitive decline was similar to a group of PD patients without DBS.	and double-blinded assessments, limits generalization of this study. Also, high dropout rates, lack of sample diversity, and enrollment from only one single academic center, pose selection bias.
Surucu, O., Baumann-Vogel, H., Uhl, M., Imbach, L. L., & Baumann, C. R. (2013). Subthalamic deep brain stimulation versus best medical therapy for L-dopa responsive pain in Parkinson's disease.	The purpose of this study is twofold: to assess whether subthalamic DBS has a similar beneficial effect on PD pain, and whether this effect can be predicted by a pre-operative L-dopa challenge test, before	Prospective analysis of DBS surgery outcomes in 14 PD patients with chronic PD-pain. 8 cases were L-dopa responsive, and 6 did not respond to an L-dopa challenge test for PD-pain control before subthalamic DBS surgery.	14 PD patients with severe PD- pain P >7 (0 = absent, 10 = maximal pain), had pre-operative L-dopa challenge test, 2-4 months before undergoing subthalamic DBS-surgery. 8 patients L-dopa responsive and in 6 patient pain did not improve with L-dopa.	For the 8 patients whose pain severity decreased with high doses of L-dopa, subthalamic DBS provided an even higher reduction (>50%) of pain severity than L-dopa alone. The majority of this group was pain-free for up to 41 months after DBS surgery. The 6 PD patients in whom severe pain was not improved with L-dopa improved less than 50% with DBS. High-dose L-dopa is inferior to STN-DBS for	Pain is subjective and assessment with an ordinal scale might not have been adequate. The placebo effect cannot be ruled out, because the study was open label. Small sample size limits the clinical findings for application in PD patients for the decision of undergoing DBS for pain relief.

Pain, 154(8), 1477-1479. doi:10.1016/j.pain.2013.03.008	DBS surgery.	The setting was the Movement Disorders Center, Department of Neurology, University Hospital Zurich.		the treatment of PD-related pain.	

REFERENCES

Abode-Iyamah, K. O., Chiang, H. Y., Woodroffe, R. W., Park, B., Jareczek, F. J., Nagahama, Y., Greenlee, J. D. W. (2018). Deep brain stimulation hardware-related infections: 10-year experience at a single institution. *Journal of Neurosurgery*, *130*(2), 1-10. doi:10.3171/2017.9.JNS1780

American Association of Colleges of Nursing. (2006). *The essentials of doctoral education for advanced nursing practice*. Retrieved from https://www.aacnnursing.org/Portals/42/Publications/DNPEssentials.pdf

Carter, A. W., Mandavia, R., Mayer, E., Marti, J., Mossialos, E., & Darzi, A. (2017). Systematic review of economic analyses in patient safety: A protocol designed to measure development in the scope and quality of evidence. *British Medical Journal Open*, *7*(8), e017089-7093. doi:10.1136/bmjopen-2017-017089

Castrioto, A., Lozano, A. M., Poon, Y. Y., Lang, A. E., Fallis, M., & Moro, E. (2011). Ten-year outcome of subthalamic stimulation in Parkinson disease: A blinded evaluation. *Archives of Neurology*, *68*(12), 1550-1556. doi:10.1001/archneurol.2011.182

Chaudhuri, K. R., Healy, D. G., & Schapira, A. H. (2006). Non-motor symptoms of Parkinson's disease: Diagnosis and management. *Lancet Neurology*, *5*(3), 235-245. doi: 10.1016/s1474-4422(06)70373-8

Cossu, G., & Sensi, M. (2017). Deep brain stimulation emergencies: How the new technologies could modify the current scenario. *Current Neurology and Neuroscience Reports*, *17*(7), 51-57. doi: 10.1007/s11910-017-0761-y

Dinkelbach, L., Moller, B., Witt, K., Schnitzler, A., & Sudmeyer, M. (2017). How to improve patient education on deep brain stimulation in Parkinson's disease: The CARE Monitor study. *Biomedical Center Neurology*, *17*(36), 1-6. doi: 10.1186/s12883-017-0820-7

Doğru Hüzmeli, E., & Yılmaz, A. (2018). Effect of deep brain stimulation on quality of life in patients with Parkinson's disease. *Turkish Journal of Neurology / Turk Norolojical Dergisi*, *24*(3), 264-268. doi:10.4274/tnd.49260

Dorsey, E. R., Elbaz, A., Nichols, E., Abd-Allah, F., Abdelalim, A., Adsuar, J. C., & Dahodwala, N. (2018). Global, regional, and national burden of Parkinson's disease, 1990–2016: A systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Neurology*, *17*(11), 939-953. doi: 10.1016/s1474-4422(18)30295-3

Dorsey, E. R., Sherer, T., Okun, M. S., & Bloem, B. R. (2018). The emerging evidence of the Parkinson pandemic. *Journal of Parkinson's Disease, 8*(s1), S3-S8. doi: 10.3233/jpd-181474

Fundament, T., Eldridge, P. R., Green, A. L., Whone, A. L., Taylor, R. S., Williams, A. C., & Schuepbach, W. M. (2016). Deep brain stimulation for Parkinson's disease with early motor complications: A United Kingdom cost-effectiveness analysis. *PLoS One*, *11*(7), e0159340-159349. doi:10.1371/journal.pone.0159340

Kalia, L. V., & Lang, A. E. (2015). Parkinson's disease. *Lancet*, *386*(9996), 896-912. doi: 10.1016/s0140-6736(14)61393-3

Knoop, C. D., Kadish, R., Hager, K., Park, M. C., Loprinzi, P. D., & LaFaver, K. (2017). Bridging the gaps in patient education for DBS surgery in Parkinson's disease. *Parkinson's Disease*, *2017*(9360354), 1-6. doi:10.1155/2017/9360354

McDonald, S., Page, M. J., Beringer, K., Wasiak, J., & Sprowson, A. (2014). Preoperative education for hip or knee replacement. *Cochrane Database Systematic Review, 5,* 1-74. doi:10.1002/14651858.CD003526.pub3

Schneider, J., Novak, D., & Jech, R. (2015, August). Optimization of Parkinson disease treatment combining anti-Parkinson drugs and deep brain stimulation using patient diaries, proceedings from *2015 37th Annual International Conference of the IEEE Engineering in Medicine and Biology Society.* Milan, Italy: IEEE. doi:10.1109/EMBC.2015.7319133

Smith, K. A., Pahwa, R., Lyons, K. E., & Nazzaro, J. M. (2016). Deep brain stimulation for Parkinson's disease: Current status and future outlook. *Neurodegenerative Disease Management*, *6*(4), 299-317. doi: 10.2217/nmt-2016-0012

Surucu, O., Baumann-Vogel, H., Uhl, M., Imbach, L. L., & Baumann, C. R. (2013). Subthalamic deep brain stimulation versus best medical therapy for L-dopa responsive pain in Parkinson's disease. *Pain*, *154*(8), 1477-1479. doi:10.1016/j.pain.2013.03.008

Taylor, D. C., & Hamdy, H. (2013). Adult learning theories: Implications for learning and teaching in medical education: AMEE Guide No. 83. *Medical Teacher*, *35*(11), e1561-1572. doi:10.3109/0142159x.2013.828153

Verla, T., Marky, A., Farber, H., Petraglia, F. W., Gallis, J., Lokhnygina, Y., Lad, S. P. (2015). Impact of advancing age on post-operative complications of deep brain stimulation surgery for essential tremor. *Journal of Clinical Neuroscience*, *22*(5), 872-876. doi:10.1016/j.jocn.2014.11.005

Yancey, N. R. (2016). Yancey, N. R. (2016). The challenge of nursing theory in the teaching-learning endeavor. *Nursing Science Quarterly*, *29*(1), 24-24. doi: 10.1177/0894318415614627